

Ian MacDonald, Public Testimony

Intro: Mr. Chairman and members of the committee. My name is Ian MacDonald, I'm a political advocacy intern at AARP, and a graduate student at UConn's School of social work.

I am here today in support of family caregivers, and for laws and regulations that support them and the essential care they provide each and every day.

I have spent the past few months talking to caregivers across the state, listening to their struggles with hospitals and healthcare providers as they try to hold their lives together during a very difficult time. In Connecticut, roughly 700,000 people are considered caregivers. They are the on the front lines, rearranging their lives and sometimes providing complex, medically-oriented tasks with little-to-no training.

Caregivers take many forms: a frail elderly woman, trying to pick up her husband who had just fallen for the fourth time this week; a loving daughter, who had to leave work early to take her mother to a cardiology appointment. A son of a single mother, who drives across state in inclement weather to make sure the woman who spent her whole life taking care of him will be safe in her home.

It seems that no one is ever quite prepared to be a caregiver, though most have some idea of what it might look like: meals, daily chores, rides to appointments, etc. However, it has been found that a caregiver's role is evolving, and the tasks they are asked to perform are becoming more complex and medically-oriented. Because of this, it is essential that family caregivers are adequately prepared when their loved one is discharged from a hospital or other health facility.

A study done in the journal of healthcare quality states that when hospitals adopt proactive, enhanced care transition interventions, assuring that family caregivers are prepared when their loved ones are discharged, the likelihood of re-hospitalization is reduced significantly.

When I hear something like this, I am reminded of a woman I talked to named Barbara. Barbara, who is in her seventies, takes care of her husband and her 90 year old mother. There have been multiple times where Barbara's husband was hospitalized 4-5 times in just a few, short weeks. He would come home, and he would fall. He would come home, and be unable to breath. He would come home, unthinkingly light up a cigarette while still attached to his oxygen, and suffer second degree burns. Each time her husband would come home, a little worse for the ware, and Barbara a little less apt to care for his growing needs.

Caregivers, like Barbara, feel like they have no say in their loved ones treatment. "Things keep piling on," is a common refrain. Words like "nightmarish" and "stressful" are others. Undoubtedly, regardless of any new law or regulation, the act of being a caregiver will always be difficult. However, I am here in support of common-sense measures that will make things a little easier for this often overlooked segment of our population:

First, the caregivers name should be documented on their loved one's medical record. They need to feel like part of the process. This small gesture can have enormous impact. Someone who

might otherwise shy away from asking important questions might, because of this measure, feel empowered to advocate for themselves and their loved one in way that didn't seem possible before.

Second, the caregiver should be notified when their loved one is being discharged home, or transferred to another medical facility. A caregiver's life is already full of uncertainty, why add to that?

Lastly, and perhaps most importantly, a caregiver needs to be provided with on site, live instruction of the tasks they are asked to perform to keep their loved ones safe and at home. They need to also be provided with a list – and detailed explanation of - resources in their area. Things like respite care, or hiring a visiting nurse.

Life is unpredictable. I am a young man, an only child to a single mother. This will not be forever. With luck, I will have the privilege of growing old. I know that I will end up taking care of her, much like the people I've talked to take care of their parents. This isn't an elderly issue, or a children's issue... this is an everyone issue. Please, give these people the serious consideration they deserve. They have worked far too hard, and far too long to be overlooked.

Thank you for your time.